

Continuous Data Collection And Electronic Devices In Clinical Research: What Do Young People Think?

Laura Lunt
University of Manchester, UK

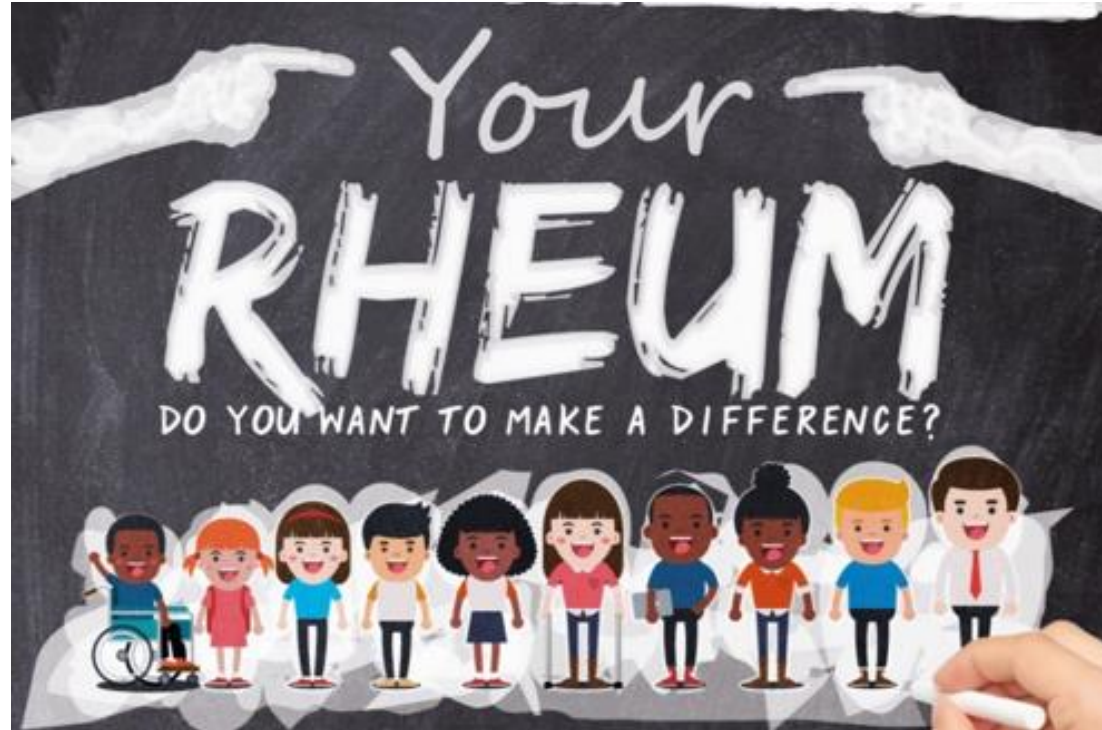
Stephanie Shoop-Worrall
Sonia Khalon
Imogen Bolger
Antoniu Fantana
Mary Short
Janet E McDonagh
Members of Your Rheum & BANNAR

Disclosures

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Picture taking is **ALLOWED** during my
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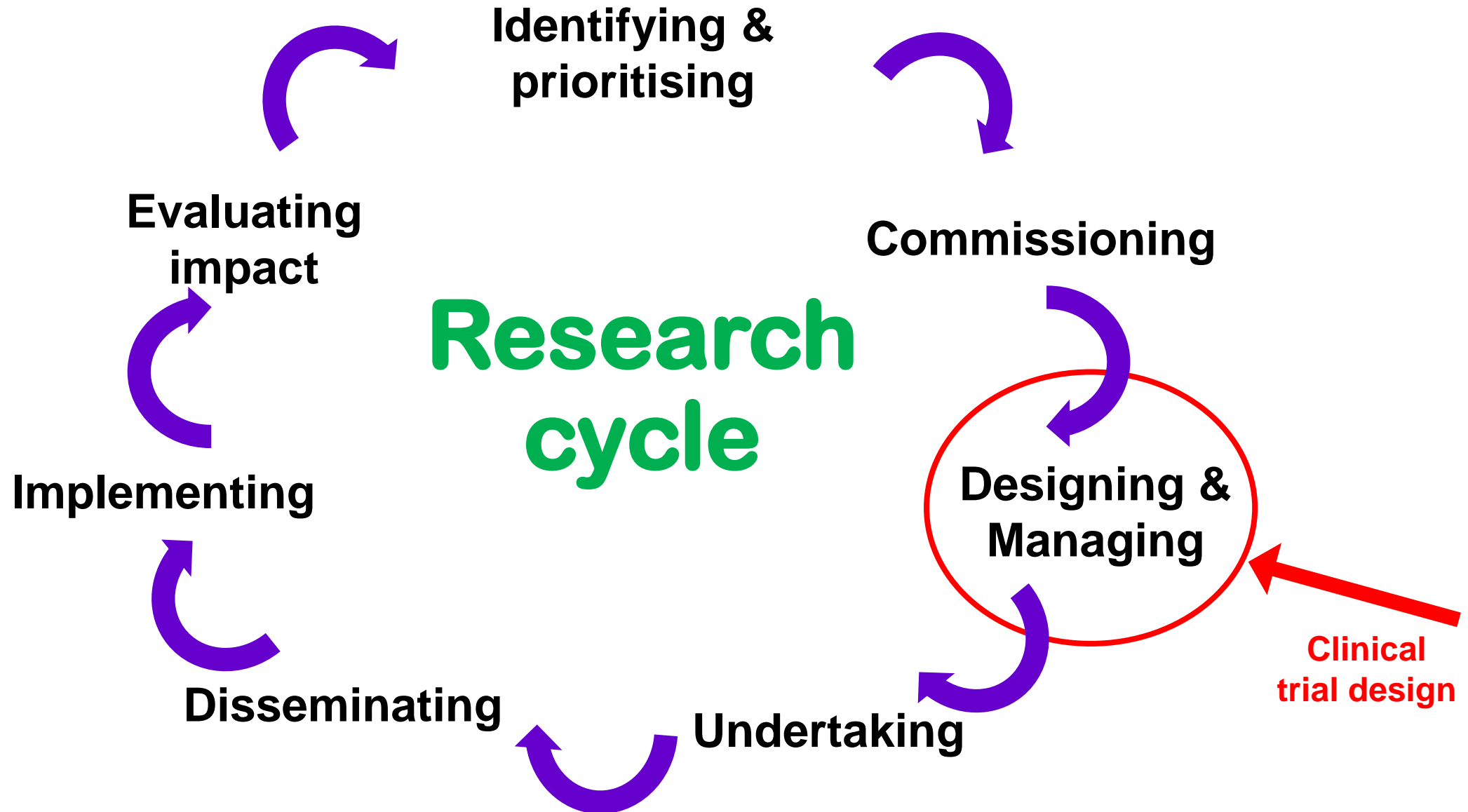




- A UK Young Person's Rheumatology Research Advisory Group
- For young people aged 11-24 years & diagnosed with a rheumatic condition
- Opportunity to get involved in research at all stages of the research cycle

Aims of the Project

1. To understand what young people think about continuous data collection for a future clinical drug trial for juvenile idiopathic arthritis (JIA)
2. To ascertain opinions from young people regarding the design of wearable devices



Methods

- 3 hour workshop
- Held in a central location in Manchester city centre
 - Accessible
 - Youth friendly
- Invited young people aged 11-24 & diagnosed with a rheumatic condition to participate via;
 - Your Rheum Group (email, website, Facebook page)
 - Clinic at Royal Manchester Children's hospital (flyers)

Workshop agenda

- Ice breakers (e.g. birthday line, spider web game)
- Large & small group discussions
- Visual aids (e.g. voting cards, emoji cards)
- Worksheets / post-it notes
- Plenty of breaks
- Facilitation



GOOD DEVICE

*What type of device(s)
would you use/wear? And
why?*

NOT SO GOOD DEVICE

*What device(s) wouldn't
you use/wear?*



*What do you want your
device to do?*

*Why wouldn't you
use/wear it?*

Results

Total of 8 young people:

- M=5, F=3, 11-19 age range
- Majority have previous research experience
(e.g. study participant, member of Your Rheum)
- All use some form of an electronic device
(e.g. mobile phone, computer game)

How does the process work?

*Important to think about
school rules and uniform
policies before picking a
device*

*Can you keep the device
after the research?*

**Initial thoughts about
collecting continuous data
in a clinical trial /
research**

*Access to your own
data*

*Non-invasive – many
people wear watches*

How is the data stored?

Invasion of privacy

*Who has access
to the data?*

Creepy

What data items are you willing to have collected?

- Joint swelling
 - Pain
 - Hand movement (use of computer games)
 - Fatigue
 - Stress/mood
 - Dizziness
 - Sickness
 - Exercise
 - Alcohol consumption
-
- **Sleep**

How long should you collect the data?

Majority of attendees would wear a device every day for 4 months.

IF...

- It is comfortable (e.g. cushion protection, adaptable for swelling)
- It doesn't vibrate or make a noise
- It has something fun or enjoyable on it (e.g. games)
- You can track your own data
- It can be put on sleep mode

Types of devices

Watch

Patch

T-Shirt

**Wireless
home
sensor**

Fitbit

Ring

Top two devices



Watch



Patch

T-Shirt

**Wireless
home
sensor**

Fitbit

Ring

Least favourite device

Watch

Patch

T-Shirt

**Wireless
home
sensor**

Fitbit

Ring

Device features (by gender)

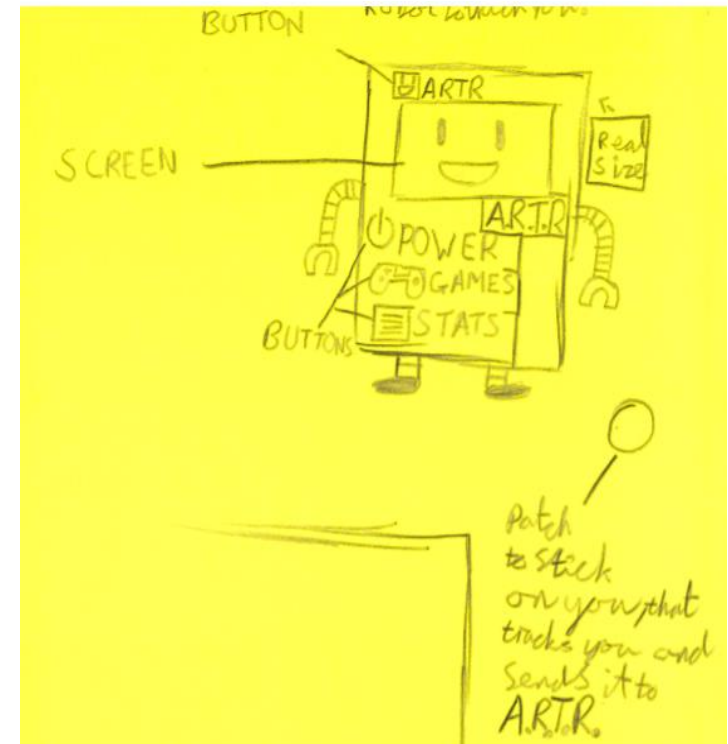
Females

- Comfortable
- As small as possible
- Moveable (e.g. can wear on stomach, arms, back)
- Waterproof
- Option to turn it off (buzz/reminder to switch back on)
- Data backup
- Weekly updates about progress (e.g. via smartphone)
- Option for messaging system (e.g. group chats, private chats with other young people)

Device features (by gender)

Males

- Ability to play games (with/without WIFI access)
- Access to YouTube
- Wi-Fi access
- Deliver medication
- Predictability (e.g. device to predict which joint to expect pain in so you can prepare)
- Dyslexic friendly



Summary

- Young people are curious about continuous data collection and raise important questions
- Gender differences in device features
- Personal and age-specific preferences

Key messages

- Young people can be involved in research, including early stages of design
- Young people have clear ideas and opinions, which are important to consider when designing research
- Working with a small group of young people can produce a wide range of views

Acknowledgements

Thank you to all of the young people who attended the workshop



Your Rheum website yourrheum.org

